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Matters related to the implementation of the Convention: informal panel discussion

Youth with disabilities

Note by the Secretariat

The present document was prepared by the Secretariat on the basis of contributions[1] of experts, received through the Bureau of the Conference of States Parties, to facilitate the informal panel discussion on the theme "Youth with disabilities", to be held during the seventh session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities.

* CRPD/CSP/2014/1.

[1] Contributions to the present document were also received from the Leonard Cheshire Disability and Inclusive Development Centre at University College London, as well as from the United Nations Children's Fund (UNICEF).

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Youth with disabilities

Introduction

1. No global data exists on the number of youth[2] with disabilities. However, estimates suggest that they constitute a significant group, with between 180 and 220 million youth with disabilities worldwide, nearly 80 per cent of whom live in developing countries, according to the fact sheet on youth with disabilities produced by the United Nations for the International Year of Youth.

2. With half the world's population below the age of 15, the number of youth with disabilities can be expected to rise markedly over the coming decades, particularly in low- and middle-income countries. Better options for medical intervention now allow a growing number of infants and children with disabilities to survive into adolescence. Improved access to treatment for accident or illness also allows many seriously ill or gravely injured children and youth to survive with disabilities. The members of military forces are disproportionately young and many receive disabling injuries. Many chronic disabling illnesses and mental health conditions first appear during adolescence. The sensory, physical and mental health impairments associated with HIV/AIDS will add millions of young people to the growing ranks of those who have disabilities and, according to the United Nations Children's Fund in its report *The State of the World's Children 2013: Children with Disabilities*, the lack of adequate reproductive health information places youth with pre-existing disabilities at increased risk of becoming HIV-positive.

3. While the issues faced by youth with disabilities were, in the past, defined in terms of medical concerns, it is now clearly recognized that disability is a cross-cutting issue and that its impact on social, economic and other human rights issues poses the key barriers in the lives of such young people.

4. There has been little empirical research on youth with disabilities as a distinct group in low- and middle-income countries and existing information from higher income countries focuses largely on formal educational or health-care systems and transition to work programmes. More attention needs to be focused on the wide array of issues faced by young people with disabilities.

5. Youth with disabilities are often overlooked in programme planning. Mainstream development programmes for youth rarely include young men and women with disabilities. Programmes for people with disabilities, where they exist, are seldom inclusive, concentrating either on children with disabilities in schools, or families, or on employment and social integration of adults with disabilities. Few address the unique social, psychological, educational and economic needs of youth.

6. The needs of youth with disabilities are strikingly similar to those of their peers without disabilities and relate to education, job training, employment and inclusion in the social, cultural, religious and economic lives of their families and communities. What distinguishes youth with disabilities are not their common needs, but the fact that these needs continue to go so largely unmet.

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[2] The United Nations defines "youth" as young people between the ages of 15 and 24. While the needs and concerns of a boy with a disability aged 15 may be very different than for a young woman with a disability aged 23, the document concentrates on the large number of issues and concerns they share.

International normative framework

7. The rights of youth with disabilities are guaranteed by the Convention on the Rights of Persons with Disabilities, adopted in 2006 and now ratified by over 140 countries, which ensures that persons with disabilities of all ages, including youth with disabilities, are entitled to all rights, including education, health care, employment, the right to vote, the right to a family life and to participate fully in the societies in which they live. The human rights of youth with disabilities are also established by a number of other instruments such as the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, and the Convention on the Rights of the Child. A host of regional, national and local legislation and policies that pertain to the inclusion of persons with disabilities have also been instituted in recent years, often in conjunction with national ratification of the Convention on the Rights of Persons with Disabilities.

8. Even in these documents however, the specific needs and concerns of youth with disabilities, as a distinct and vulnerable group, are assumed but rarely mentioned. For instance, the landmark World Programme of Action on Youth, of 2010, though applicable to youth with disabilities, includes just a few specific references to youth with disabilities, only in the context of employment and information technology.

Issues and challenges

Stigma

9. Globally, one of the greatest impediments to youth with disabilities is stigma, which leads to social isolation and discrimination. Societal discrimination and negative attitudes arise from misconceptions, stereotypes and folklore which links disability to punishment for past sins, misfortune or witchcraft. Community members (family members, neighbours, community leaders, teachers, health-care workers and others) who hold such views may distance themselves from children and adults with disabilities and their families and limit or prohibit their participation in community life. Families of children and youth with disabilities may respond by keeping them hidden at home or sending them to institutions, where these exist, both in response to such prejudices and in an attempt to protect their children. Understanding and addressing stigma is a critical step to improving the lives of all persons with disabilities.

Poverty

10. While any family can have a child with a disability, disability disproportionately affects the poor. The lack of medical care, nutritious food, basic water and sanitation, adequate housing and safe neighbourhoods increases the risk that a child in a poor family will be born or become impaired.[3] Families with a child with disabilities are more likely to face poverty, not only through additional

[3] Nora Groce, Maria Kett, Raymond Lang and Jean-François Trani, "Disability and Poverty: the need for a more nuanced understanding of implications for development policy and practice" *Third World Quarterly*, vol. 32, No. 8 (September 2011).

demands on household income for medical care and disability-related expenses, but also because parents and family members may take on caregiving roles, which generally means that one parent or family member (generally female) may give up income-generating activities in order to stay home and provide support. The result is that households with members with disabilities generally have lower incomes than other households and are more likely to live below the poverty line.

Health care

11. Access to health care is important for all young people and this is no less true for youth with disabilities. For these young people, there are two areas of concern: lack of access to general health care and for some, lack of access to disability-specific care (for example, rehabilitative services and assistive devices such as wheelchairs or hearing aids).

12. General health care is a problem because in many cases, health-care facilities are simply inaccessible. For example, stairs block access for wheelchair users, or there are no sign language interpreters. Health-care workers are often unfamiliar with the needs of persons with disabilities and hesitate to take on routine care, mistakenly believing that specialist care is always needed.

13. Public health education programmes often are not designed to include youth with disabilities: radio campaigns are inaccessible to deaf individuals; witty, fast-paced advertisements for safer sex are lost on some young people with intellectual disabilities. This is a lost opportunity, particularly when a growing body of research, including studies based on the National Education Longitudinal Study of 1988 (United States of America) and the World Bank/Yale University global survey on HIV/AIDS and disability, clearly shows that youth with disabilities are at equal or greater risk for smoking, alcohol consumption and unsafe sex.

14. Rehabilitative services are limited or non-existent in many countries and, where they exist, tend to be concentrated in urban areas and to be prohibitively expensive. In societies where young women are not allowed to travel or live away from home unaccompanied, accessing such services is not permitted unless they are accompanied by a male relative.

15. Assistive devices (such as artificial limbs, wheelchairs, hearing aids or glasses) are often unavailable, or may be expensive. The latter is particularly problematic for adolescents, who may require regular replacements as they grow. The issue is not simply cosmetic. A poorly fitting artificial limb has profound psychological and social implications for an already marginalized young person. A wheelchair that has become too small limits the ability of a young person to leave the house to attend school, work or establish any measure of autonomy.

Education

16. Lack of education is a key concern for most youth with disabilities. Despite clear calls for universal education in the Millennium Development Goals and the Convention on the Rights of the Child, and for education for children and youth with disabilities in the Salamanca Statement and Framework for Action on Special Needs Education, adopted at the World Conference on Special Needs Education: Access and Quality, youth with disabilities continue to attend school at rates far lower than their non-disabled peers, they are more likely to drop out of school and

even those who complete their courses often learn far less than their classmates because of a lack of resources, teachers who are untrained in how best to educate children with disabilities and as a result of low expectations.

17. Awareness-raising and capacity-building programmes for teachers to prepare them to adequately teach children and adolescents with disabilities are rare. Physical barriers also remain. If the schools, their facilities and related services such as transportation are not designed and built in an manner accessible to all service users and learners with different needs and functional situations, many youth and children with disabilities will continue to be unable to attend. A lack of trained teachers or appropriate teaching materials or methods limits access to education for millions children and youth with disabilities, as well as those with mental health difficulties.

18. For many youth with disabilities, the cumulative lack of adequate primary education results in poor performance on standardized exams, which blocks their ability to go on to higher education. By the time children with a disability reach early adolescence, the vast majority find themselves far behind the educational and skill levels of their non-disabled peers.

19. Apprenticeships and job training are additional areas of concern. Unlike non-disabled youth, youth with disabilities find it particularly hard to get apprenticeships or job training that would enable them to enter the workplace. Should they not succeed in an initial apprenticeship or be fired from their first job, those around them are quick to label them unemployable and refuse to let them try again.

Employment and economic livelihood

20. Young people worldwide are at higher risk for unemployment, partial employment or full employment at lower wages than adult workers. Adolescents and youth with disabilities are at even greater risk. Entering the job market with little education and few or no skills, youth with disabilities have difficulty competing. For most, social prejudice and a lack of accurate information on the potential productivity of persons with disabilities makes employers hesitant to hire them. For some, specific physical or intellectual impairments may further limit their job options.

21. The employment rates of youth with disabilities are rarely tracked. However, rates of unemployment among adults with disabilities, on average, tend to be some 40 to 60 per cent higher than for the non-disabled population. As noted in the fact sheet on youth with disabilities, the International Labour Organization estimates that the unemployment rate among people with disabilities in the developing world is as high as 80 per cent in some countries.

22. Not only is their employment status in a continual state of flux, but young people with disabilities are also more likely to be hired for jobs that require little training and have few opportunities for advancement. As reported in a fact sheet on children and young people with disabilities, prepared by the United Nations Children's Fund in 2013, even when well educated, young people with disabilities take longer to find a position, have less job security and less prospect of advancement than do their peers without disabilities. This is true even for individuals with a disability who have received a university education.

23. Citing employment figures only however, may be misleading. Presumably, only those whose disabilities are very severe or who are from wealthy families do not contribute to their households in some way. Millions of young people with disabilities worldwide work, although they are officially classified as "unemployed". Millions work in the family home, farm or workshop. Millions more work doing odd jobs in the community or working as beggars.[4] Such work, even when of great financial significance to the household, may go unnoticed by economists, local communities and even by their own families.

Social inclusion and participation

24. The years between the ages of 15 and 24 are developmentally critical for young people, as this is the period when most begin to establish their own identities and autonomy, establishing relationships while moving from their parents' home and setting up households and families of their own. Yet many youth with disabilities are not included in activities that build fundamental social, educational and economic skills. This exclusion distinguishes young people with a disability from all other groups of young people in every society.

25. Young people with a disability often have little or no say over where they will live, whom they will live with and what role they will play within their families or communities. They are often denied the right to marry or to build families of their own. Indeed, in some countries, individuals with certain types of disability are unable to legally obtain a marriage licence.

26. This does not mean that young men and women with a disability are not involved in relationships, or do not engage in sexual activities, but it often means that there is no social acknowledgement for such activities and furthermore, that no information on relationships or sex education is provided to them, as reported by the World Health Organization and the United Nations Population Fund in their guidance note on promoting sexual and reproductive health for persons with disabilities. This places adolescent girls and young women with disabilities at increased risk for pregnancy, and young men and women with disabilities at increased risk for abusive relationships and sexually transmitted diseases, including HIV/AIDS.

27. Social participation and civic engagement is also often limited or denied to youth with disabilities. Civic groups, community associations or political activities are rarely designed to be accessible to youth with a disability. Without inclusion in the social and civic life of their communities, young women and men with disabilities often lack a voice or a vote in how their communities are run or in decisions that will affect them and their families in future.

Other cross-sectoral issues

28. Disability does not exist in isolation, but must be considered in conjunction with other pressing development issues. Young people with a disability who are members of ethnic and minority populations and those who live in rural areas or urban slums also face multiple disadvantages. These young people are less likely to

[4] Nora Groce, Barbara Murray, Marie Loeb, Carlo Tramontano, Jean-François Trani and Asfaw Mekonnen, "Disabled Beggars in Addis Ababa, Ethiopia", Employment Working Paper, No. 141 (Geneva, International Labour Organization, 2013).

be included in whatever mainstream or disability-specific services and programmes exist for youth, compounding the marginalization and discrimination already encountered. Young women with disabilities in such populations are at even greater disadvantage.

29. Violence and abuse is another area of great concern. Youth with disabilities are at significantly increased risk of violence and abuse. Not only have many young people been initially disabled through violence, but once disabled, these individuals are at significantly increased risk of being victims of physical and psychological abuse, domestic violence and rape. They are also at increased risk of being trafficked into sexual slavery. Youth with disabilities are at increased risk because they are often unable to protect themselves and because many abusers believe that such young people will be unable to report the abuse or will not be believed should such abuse be reported.

30. The social isolation, lack of education, poverty and discrimination faced by youth with disabilities sets up an interconnected pattern of problems. Millions of these young people end up on the street, unemployed and often involved in crime, sex work and drugs, frequently at the behest of others who see them as easy prey. It is estimated that at least one-third of all street children have a disability.

31. One additional area of particular concern, and potentially of great promise, to youth with disabilities is new information and communications technologies. Computers, mobile phones and tablets allow many youth with disabilities, for the first time, to communicate with the world around them, linking them to social networks and allowing them to access information even if they are unable to leave their room. However, evolving technologies must be designed to be accessible, and youth with disabilities must have the literacy skills and technological training to understand how to use this technology and the resources to be able to purchase and maintain it.

The way forward

32. A holistic approach is needed. There is a need to include youth with disabilities in all mainstream development efforts that target youth. There is also a need for specific and targeted actions and interventions to combat against discrimination, remove barriers and create enabling conditions for their full participation in development and society.

33. While there are an increasing number of programmes that address the specific needs of youth with disabilities, globally the number of such programmes remains small. Organizations run by and for people with disabilities exist in all countries and are a powerful advocacy base for change. But few such organizations have organized systems of youth groups or internship or training programmes whereby young people with disabilities are systematically brought into the organization to represent the voice and concerns of youth with disabilities or are trained to begin to assume leadership roles in future. More systematic outreach to youth with disabilities would add an important and currently poorly represented component to effective disability advocacy efforts, and such efforts must be fostered and funded.

Listen to youth with disabilities

34. Effectively addressing the concerns of youth with disabilities requires listening to the voice of youth with disabilities and proactively involving them in development, including relevant policy and decision-making processes.[5]

35. In 2013, the Division of Social Policy and Development of the Department of Economic and Social Affairs undertook a consultation with the Leonard Cheshire Disability Young Voices Programme. The Programme brings together over 1,200 youth with disabilities to campaign both nationally and internationally for disability rights, and the consultation involved a survey conducted among young disability advocates, aged 16 to 25, from countries around the world.[6] The 75 young adults who took part in the consultation reflected the global Young Voices membership, a balanced number of young men and women with a range of disabilities. These young people responded with their ideas, stories, photographs and comments and raised many issues and concerns. Their call for action focused on a series of key requests:

(a) Treat young people with disabilities equally and with respect: disability is not inability;

(b) Raise awareness among youth and society as a whole about the rights of youth with disabilities and open up opportunities for their participation;

(c) Remove environmental barriers that stop youth with disabilities from participating;

(d) Acknowledge the greater risk of abuse and violence against girls and young women with disabilities. Raise awareness around their vulnerability, reinforce laws to protect them, and provide support to empower them to speak out for themselves;

(e) Reach out to the hardest to reach, ensure education for all covers young people with disabilities, giving them a chance to reach their potential especially through support to schools and families to accept the value of education for children and youth with disabilities;

(f) Ensure equal opportunity and support youth with disabilities to participate in policy and decision-making forums and processes at all levels;

(g) Create opportunities for youth to take part in sports and other recreational activities, with a view to challenging negative stereotypes and promoting social integration;

(h) Support the development and promotion of accessible technologies that facilitate the participation of young people with disabilities;

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[5] The seventh annual Children's Summit in Rwanda, held in Kigali in 2012, was a good example of involving youth with disabilities in national economic development policy consultations. Children and youth with disabilities represented 20 per cent of the more than 500 delegates at the Summit, which included national parliamentarians and Government officials including the Prime Minister, Pierre Habumuremyi. Recommendations from the Summit were included in Rwanda's first Economic Development and Poverty Reduction Strategy and in the action plan of the Ministry of Gender and Family Promotion.

[6] More details are available from http://undesadspd.org/Youth/ResourcesandPublications/YouthWithDisabilities.aspx.

(i) Promote disability-inclusive international development. All development policy frameworks and programmes should include a disability perspective and address the rights and concerns of persons with disabilities, including through taking proactive measures;

(j) Celebrate diversity. Recognize the important role young people with disabilities play in creating richer, more dynamic, resourceful and respectful communities.

36. The recommendations could provide an important starting point to ensure that youth with disabilities are included in all efforts of development to improve the lives of people worldwide. Above all, unless millions of youth with disabilities are included in all development efforts up to and including the emerging post-2015 development goals, the rights delineated in the Convention are unlikely to be fully realized and the economic and social benefits sought for all through the Millennium Development Goals and all other internationally agreed development goals could not be met.

Questions for consideration

37. The following questions are presented for the consideration of the panel:

(a) What examples exist at the national and local levels with regards to the implementation of practical actions to ensure the rights and needs of youth with disabilities are included in policy and practices on the ground?

(b) What concrete policies and actions proved to be successful and could be replicable by Governments to realize universal education for children and youth with disabilities since they have been known as the hardest to reach in the national efforts for achieving universal education?

(c) Which policies work in terms of effective promotion of employment for youth with disabilities?

(d) Are there any good practices in proactively involving youth with disabilities in development policymaking forums and processes?